

Supporting families affected by chronic granulomatous disorder

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May e-news

Dear CGD Society member,

We would like to welcome you to our latest e-news and would like to wish a warm hello to all our new members.

Latest news

UK Government launches COVID-19 antivirals taskforce

The Antivirals Taskforce will identify treatments for UK patients who have been exposed to COVID-19 to stop the infection spreading and speed up recovery time. <u>Find out more</u>.

Mental Health Awareness Week



This week (10 – 16th May 2021) is mental health awareness week with this year's theme being nature. It is so important that we all look after our mental wellbeing, especially after such a long and difficult year. It is well documented that being outside amongst nature has a positive impact on your mental wellbeing. The Mental Health Foundation provide some great resources to mark this week.

We also have a <u>list of resources</u> you can contact if you or someone you know needs support right now.

A fond farewell and thank you



We are sad to announce that our Technical Director, Dr Susan Walsh is leaving us after 19 years of working with us at CGD Society. Susan will be now focusing her time as CEO of the newly named Immunodeficiency UK, previously known as PID UK.

Susan's impact on our charity has been huge and her hard work and dedication over the years has resulted in many research and clinical trails for treatments and potential cures for CGD. In fact, since 1997 we have invested nearly £3.5 million in research into CGD. Susan also represented us at many events and gave excellent speeches on research and CGD, including a speech at the House of Commons! Susan also attended many of our family weekends and get togethers and got to know our CGD families.

Susan will be sorely missed, especially by myself. I have known Susan for many years and remember her well when my child was diagnosed with CGD and we attended the family weekends. I am sure we will keep in touch.

On behalf of all trustees, Helen, Adelle and our many members I want to wish Susan every success in her role at Immunodeficiency UK and thank her for all her hard work over the last 19 years.

Claire Jeffries, Operations and Fundraising Manager

Our 30th year



As you may be aware this year marks the 30th year of our charity. Starting as a small support group back in 1986 we have seen the charity grow and evolve to the needs of the CGD community.

We are planning a few events to mark the occasion and we would love to hear from you all on how our charity has supported you. It could be how informative you have found our website, the advice you have received through our email and telephone helpline or the support you received from our CGD Clinical Nurse Specialist. All you need to do is provide us with a small quote that we can feature on our website, social media and newsletters as part of our 30th celebrations.

Please email Claire at <u>hello@cgdsociety.org</u>

Your fundraising

Without our supporters and fundraisers, we would not be able to support the CGD Community like we do. Every donation and fundraising event held brings us one step closer to our aim – a cure for ALL with CGD.

The 10K steps feel good challenge 2021

We would like to say a huge thank you to people taking part in this challenge. The aim is to do 10,000 steps a day in May to help us raise funds.

Carly Koncuk introduced this challenge to us and has since set up her Just Giving page: <u>Just Giving Carly Koncuk</u>. Carly and her husband Kadir have been doing great achieving their 10,000 steps a day so far. Carly is an X-Linked CGD Carrier and her son Ayden received a BMT (Bone Marrow Transplant) for CGD. You can <u>read Ayden's story here</u>.



We also have Bonnie Burgess-Biggerstaff, sisters Emily and Amy and their mum Mary-Rose taking part. Bonnie's two sons, Ben and Bobby were recently diagnosed with CGD and Bonnie and her family are keen to support our charity any way they can. They have done an amazing job so far and have raised an incredible £8,758.51 (including gift aid): <u>Just Giving Bonnie Burgess-Biggerstaff</u>

Thank you once again to you all for taking part for us here at CGD Society. We are truly grateful.



Want to be part of our incredible fundraisers?

Now is your chance to take part in the historical event that is the London Marathon, all be it virtually. We have secured 5 places in this years Virtual London Marathon taking place Sunday 3rd October. So, if you would like to sign up or if you have any family or friends that would like to take part <u>full details can</u> <u>be found here</u>.

Thank you for taking the time to read this latest edition. If you would like to make contact with us you can at <u>hello@cgdsociety.org</u> or call us on 0800 987 8988

Best wishes,

Claire, Adelle and Helen



Sponsored by a grant from Orchard Therapeutics



Call us on: 0800 987 8988

Email us at: <u>hello@cgdsociety.org</u>

Write to us at: CGD Society, PO Box 454, Dartford, DA1 9PE

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